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## Abstract:

Young women growing up within the context of familial breast cancer are faced with significant psychosocial challenges. The most profound of these are the temporary absence, and permanent loss, of their mothers. Eighteen young women (aged 18-34) from rural Victoria (Australia), with family histories of breast cancer, were interviewed for this study. The data were analysed using hermeneutic Heideggerian phenomenology to explore their lived experiences. Our findings reveal the long-term and pervasive consequences of relational distress associated with the temporary and permanent loss of mothers. This distress is experienced through disruptions to developmental attachment, and embodied and biographical identity. We highlight how familial breast cancer extends beyond genetic inheritance to encompass the relational distress of loss and grief. We conclude by highlighting the importance of considering the ways in which temporality, self-identity and daughters' ways of seeing themselves are significantly altered by their mothers' cancer experience.

**Key words:** Cancer, Relational distress, Maternal absence, Identity, Phenomenology

## **Relational distress and maternal absence: Young women's lived experience of familial breast cancer.**

### Introduction:

Cancer presents major social and emotional challenges, which affect those diagnosed as well as family, friends and community members (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2012). Family members, in particular daughters, experience high levels of emotional distress and role disruptions (Bekteshi & Kayser, 2013; Foran-Tuller, O'Hea, Moon, & Miller, 2012; Ginter & Radina, 2014; Lightfoot et al., 2005; Rainville, Dumont, Simard, & Savard, 2012; Wenzel et al., 2012; Wiggs, 2011), with implications for the developing child. One in two Australians will develop cancer, and one in five will die from it before the age of 85. In 2012, 14,560 new cases of breast cancer were diagnosed in Australia alone (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2012). The incidence and prevalence of cancer in Australia reflects the current international cancer trend (Cancer Research UK, 2012).

The American Cancer Society noted in 2011 that, whilst breast cancer and its impacts are highly researched, "...its devastating impact on family members, especially daughters, remains a surprisingly unexplored terrain" (2011: xi). Relationships are central in people's lives (Becker, 1992), and define who we are. For young women, mothers are one of the most important relationships in their lives (Johnson, 2012). When growing up within the lived experience of familial breast cancer, young women are faced with untimely and traumatic complexity; the most profound of these consequences is evidenced in the mother/daughter relationship (Bekteshi & Kayser, 2013; Clemmens, 2009; Edelman, 2006; Foran-Tuller et al., 2012; Oktay, 2005; Vodermaier & Stanton, 2012).

Given this statistical snapshot, and the significance of cancer on the mother daughter relationship, the concept of relational distress has resounding relevance. Relational distress refers to a life event in which a child's sense of emotional and/or physical safety has been ruptured by situational or behavioural factors related to primary caregivers (Sheinberg & True, 2008). Relational distress has often been viewed in light of incest, sexual abuse, and domestic violence, but only in a limited scope to familial cancer (Clemmens, 2009). Thereby relational distress could extend ways to understand daughters' experiences of familial cancer.

Existing literature highlights that disruptions to developmental attachment (Bowlby, 1969, 1988) can create, or heighten pre-existing, anxiety (Howe, 2011). A mother's diagnosis of breast cancer, particularly when children are still dependant, is a significant threat to the security of that relationship (Foran-Tuller et al., 2012). The concept of a secure base (Bowlby, 1969, 1988) from which the child can explore the world no longer exists. As a result of illness and medical treatment children not only emotionally lose their secure base, but they are also unable to maintain physical proximity to their primary attachment figure (Bowlby, 1969). This can contribute to heightened levels of anxiety and separation distress (Bowlby, 1969). This has not specifically been explored in relation to daughter's experiences of familial cancer. Although Clemmens (2009), who explored adolescents experiences of a maternal cancer diagnosis, found increased levels of anxiety within, but also a strengthening of, mother/daughter relationships. This experience has also been noted in other research (Bekteshi & Kayser, 2013; Johnson, 2012), which acknowledge and explore the impact of cancer on the mother/daughter relationship.

For the individual daughter, there are further fears around embodied identity (Merleau-Ponty & Smith, 1962). Embodiment can be defined phenomenologically as how we live in and

experience the world through our bodies (Merleau-Ponty & Smith, 1962). There is an undeniable shared and gendered bodily connection between mothers and daughters, referred to as inter-embodiment by Jenkins and associates (2013). According to Bell (2009) ‘daughters make sense [of themselves] by drawing from dominant discourses and creatively reworking, reconfiguring and resisting them’ (pg. 10). When considering daughters experience of familial breast cancer, daughters sense of embodiment can be reshaped ‘by their definition, and medicines definition, [that] they have medically deviant and socially non-normative bodies’ (Bell, 2009: 12). Drawing on the literature of Lupton (1995) and Nettleton (1995), and feminists more generally, women’s embodied identities have been well documented in the literature as personal, political and symbolic. This has relevance for understanding daughters embodied experiences of familial breast cancer.

Biographical disruption, and the role chronic illness plays in creating such disruptions, is well documented in medical sociological literature (Bury, 1982). Specifically, a mother’s diagnosis of breast cancer creates disruptions to a daughter’s biographical identity, which “fundamentally calls into question the individual’s sense of self, their relations to others and their life course trajectory” (Jenkins et al., 2013: 530). Biographical identities are often expressed through illness narratives. Such narratives serve as a critique of medical model dominance, and allow for complex and nuanced interpretations (Bury, 2001). It is well documented in the literature that illness narratives can assist in storying and re-storying the self, and this can lead to new understandings (Frank, 1995; Kleinman, 1988; Little, Jordens, Paul, & Sayers, 2001; M Little, K Paul, C Jordens, & E-J Sayers, 2002; M Little & E-J Sayers, 2004; Stacey, 1997).

Cancer narratives have also been well explored (Kleinman, 1988; Little et al., 2001; M Little et al., 2002; M Little & E-J Sayers, 2004), but predominantly from the perspective of the patient and not specifically from daughters’ perspectives. Following the work of Frank (1995), the

concepts of heroic, restitution and chaos narratives can assist understanding of the altered biographic identity of daughters. In this article we directly explore the impacts of temporary and permanent loss from the perspective of daughters within the context of familial breast cancer. We posit that the altered mother daughter relationship, as viewed from the daughters' perspective, has long term and pervasive consequences for daughters' ongoing relational distress. Taken together, the impacts on developmental attachment, embodiment and biographic identity disruptions constitute ways of conceptualising relational distress throughout this significant life experience. Furthermore, we suggest a Heideggerian perspective offers a unique insight into daughters' lived experience when confronted with maternal absence.

#### Methods:

Hermeneutic phenomenology, an approach based on the work of Heidegger (1962), was chosen for its focus on awareness of subjective human experience, meaning-making, and understanding holistic ways of Being-in-the-World of familial cancer (Streubert & Carpenter, 2007). We used Heideggerian phenomenology as a qualitative research method in order to gain an in-depth understanding of participants' subjective experiences, through capturing participants own words and reflections, and the meanings they ascribed to the familial cancer experience. This approach allowed for an interpretive, rather than a descriptive, stance and afforded an in-depth understanding of the complexity experienced by the participants (Steeves, 2000). The hermeneutic circle of analysis was used as a data analysis technique to identify key themes in participants stories as well as relevant Heideggerian principles. These included Being (that is, the actions and reflections of self), Being-with (key relationships with others, and associated losses), Angst (the consequence of attachment disruption) and Temporality (biographies). All of these related to a disruption to self and a fracturing of relationships.

## Sampling:

Ethics approval was gained from the La Trobe University Human Ethics Committee prior to the commencement of this study. Consistent with both qualitative and phenomenological research methods, purposive sampling (Streubert & Carpenter, 2007) and volunteer sampling (Liamputtong Rice, 2013; McKenzie, Neiger, & Smeltzer, 2005; Petersen & Lupton, 1996) were used to recruit eighteen participants who had a self-reported family history of breast cancer or self-reported medically confirmed risk (such as BRCA1 or BRCA2) of familial breast cancer (Table 1 provides a summary of participant characteristics). Participants were recruited from non-metropolitan centres in Victoria, Australia, through advertisements in local newspapers and on Facebook, and placement of posters in women's health centres, University notice boards, community spaces and local businesses. The site of the research was a non-metropolitan University, and the participants were recruited from the local, regional area, partly to engagement the local community, but also for pragmatic and feasibility planning, given the widespread, geographic context in Victoria, Australia. Participants needed to be aged 18-34 years, reside in Victoria, Australia and have a self-reported family history of breast cancer or high risk classification.

Table 1. Participant characteristics

## Data collection and analysis:

Semi-structured interviews were chosen to gain an in-depth understanding of young women's lived experience of familial breast cancer. This data collection method encouraged participants to share aspects of their experience that they perceived were important and valuable (Minichiello, Aroni, & Neville-Hayes, 2008), giving them a voice in an under-researched area. Prior to the commencement of the interviewing process a semi-structured interview schedule

was developed from the literature and the researcher's own knowledge and experiences. This document was further amended throughout the interview process to reflect important aspects raised by participants. The interview schedule was only used as a guide and did not dictate a strict path for the interview (Clough & Nutbrown, 2007; Wimpenny & Gass, 2000), thus the research remained participant focussed. Participants volunteered to undertake a one hour, face-to-face, audio-recorded interview that was transcribed verbatim and analysed to identify the key themes.

Given the sensitive nature of the research interviews, we were concerned with causing further possible distress. In order to minimise distress, we provided clear participant information sheets, alerting participants to this possibility and that we would pause or discontinue the interview if matters discussed were too painful. We also provided cancer and crisis help-line phone numbers, as well as local community health and counselling details. Researchers were offered peer-debriefing and access to La Trobe University counselling services if needed. To our knowledge, whilst some participants were tearful or sad, none were distressed requiring professional intervention.

The hermeneutic circle of interpretation is a circular process, which focuses on examining narratives simultaneously with the emerging interpretation, whilst making sure never to lose sight of each participant's particular story and context (Streubert & Carpenter, 2007). This process involves naïve reading, structural analysis and interpretation of the whole (Streubert & Carpenter, 2007) and continues until thick description is achieved. That is, a full and rich understanding that accurately captures and communicates the meaning of the lived experience for the participants being studied is captured (Cohen, Kahn, & Steeves, 2000). All transcripts were read and analysed individually by NJ (author 1) to ensure the full context of each individual story was grasped. All transcripts were then considered together to identify key Heideggerian themes.



### Findings:

In this section we outline the familial cancer experience from daughters' points of view. For the purposes of this paper, we have decided to present extensive quotes to illustrate key themes, with pseudonyms indicating each participant's contribution. We have tried to maintain the participants' voice as distinct from our Heideggerian interpretations. This is because we wish to honour the voices of the participants (whilst we acknowledge we are, of course, reauthoring their voices), and not privilege theory over experience (Pascal, 2006).

The key findings focus on the experience of loss; both temporary loss due to treatment related absences and/or permanent loss as a result of bereavement. Although we have not specifically focussed on rurality as a sociological concept, it is worth noting that the rural residential location of participants influenced their familial cancer experiences. This was particularly important when mothers relocated to metropolitan areas for treatment, further exacerbating the experience of absence. Of note was that the most profound loss for participants was not only the immediate fear of cancer, but also the ongoing relational distress created in the aftermath of diagnosis, and its effects on the mother daughter relationship.

### Temporary loss and role change

Participants identified a range of complex experiences of maternal absence in their lives. For some, the absence was temporary and a direct consequence of their mothers' geographic relocation for treatment. Many participants lived outside a metropolitan or regional city and needed to travel several hours for access to treatment facilities. Although such absences were

painful and confusing, daughters' hoped that life would eventually go back to 'normal' once their mother returned to their home. Participants struggled with the physical absence of their mother and the consequent changes in the household, such as structure, routines and responsibilities. The isolation and fear experienced was, in part, a result of the disruptive cancer diagnosis, but also the lack of emotional support, that was usually provided by their mothers during challenging experiences. As participants explained:

“As well as not knowing what to feel with what was going on, you have a whole upheaval with a new structure in your home....it just added to the pain and confusion...” (Jennifer)

“It's been pretty hard being away from my mum...I suppose that was probably the hardest thing about it; being removed from mum when I wanted to be there with her.” (Donna)

These difficulties were further intensified if/when daughters were privy to both the internal and external 'suffering' associated with a cancer diagnosis and treatment. In particular, those daughters who observed their mothers experiencing significant physical suffering reported feeling greater fear and distress. Despite awareness that these effects may only be temporary, and that their mothers may return to full health, the impacts of being exposed to this 'suffering' were significant.

“When she lost her hair and when she had chemotherapy, I think that it [fear] really set in, cause then she started to look sick.” (Sophie)

“It was hard seeing her going back to [being] like a child, that's what I struggled with the most, her losing her ability to do things for herself. Mum was always a

very, very independent person and seeing her like that was very traumatic.

(Bethany)

“The person I loved more than anything started to disappear before my very eyes. She had a really hard time on chemo and fought so hard, but it was too much. Losing her hair, lethargy, nausea, ulcers and everything else that came with it, it was just cruel and scary. Neither of us could do anything to make it better or to change the outcome.” (Rachel)

The family unit, and the family home, had previously provided a sense of comfort and security. Many participants were aged between 8 and 12 years old when their mothers were diagnosed, and this was significant for their developmental stage of emotional dependence on, and attachment to, their parents. Unlike teenagers and young adults who are more physically independent, for younger children parental absence affected their ability to travel to school, participate in sports, socialise with friends, fulfil their roles and responsibilities around the home, and threatened their sense of emotional security, comfort and normality. Even with the chance of good prognosis, there was an element of loss and grief for their once healthy, and practical, mother.

“I was really busy with my first full time job and so I don’t remember much of her being gone except that there was no-one to cook dinner and we had to do our own washing...probably more the logistics of it.” (Linda)

“The morning routine would be me waking up, getting my brother out of bed, getting us both ready for school, getting lunches together, getting mum brekkie in bed because she couldn’t move and we’d head off to school....I took on the mother role in that respect.” (Bethany)

“Our life was we’d get home from school, we’d have dinner and we’d go to the hospital.

That was how I spent every single evening for four years.” (Amy)

Participants made significant alterations to their everyday lives in an attempt to minimise the impacts of the absence of their mothers and to try to maintain daily functioning. They sought involvement in their mothers’ treatment as a way of reducing some of the ‘unknowns’ that increased their anxiety. For some, this meant having regular family conversations to make sure that everyone understood what was happening. For others, it meant absenteeism from school, work and other responsibilities, as they felt it more important to have regular physical contact with their mothers, even relocating for treatment with their mother/family.

“I was trying to spend as much time in Melbourne as I could because she was down there for six weeks at a time. Spending time down there I just missed school altogether because I didn’t want to be up here while she was down there.” (Laura)

Relocation facilitated a sense of control over the physical absence and a sense of security in being together. Role reversal, where daughters had the responsibility of becoming the carer, was common, and aided the participants in feeling they had a role and a purpose.

“It felt good to be able to help her. It just made me feel like I was doing something whereas before I just felt powerless; I didn’t know what to do, what to say....” (Bethany)

“I think it was my turn to care for mum, not mum to care for me... It was about me becoming mum for mum; to look after her and my sister.” (Claire)

“Dad would end up sleeping on the couch and I used to sleep in the bed with mum. I would get up in the middle of the night and get her heat packs and stuff like that....I definitely became her main carer.” (Linda)

Not only was the physical loss profound but this was exacerbated by the emotional emptiness; that is, the absence of the mother from her every-day relationship role. Participants emphasised that once their mother was ill, their relationship changed. This absence of friendship, nurturing, guidance and security created a heightened awareness of what was missing from the mother/daughter relationship.

“She asked you know, don’t bring your shit on to me when I am going through this. That’s hard...my mum’s a huge support network for me. I really depended on her and I didn’t realise how much I depend on her until she said ‘I can’t support you at the moment.’” (Donna)

The absence of what was perceived as a ‘normal’ physical and emotional relationship was distressing, more so than witnessing the cancer diagnosis and treatment. Mothers, who would usually be available to emotionally support their daughter through such crises, were emotionally and physically absent, and too unwell to do so. Daughters felt fearful about the losses they were experiencing and possible future losses, but also felt guilty about acknowledging these fears.

“I remember laying in bed at night and imagining her funeral, and feeling bad about doing so....” (Jennifer)

That the mothers’ illness was the source of their distress made this emotionally harrowing. Participants became conscious that their world had fractured as a result of their mother’s illness and their awareness of her possible death.

**Permanent loss and life course challenges**

For others, the maternal absence was permanent due to maternal death. For these participants, breast cancer was no longer the defining element of their family history. Participants' entire sense of self and their world were permanently altered; they felt the pain of their mothers' absence daily and it shaped their past, present and future relationships and identity.

Some participants had lost their mothers when they themselves were young children, and their mothers were under 50 years of age. They perceived that the consequences of maternal loss would remain with them for the rest of their lives; there was no closure or getting over it. For these women, the cancer experience itself was secondary to their bereavement. Participants reported that maternal loss continued to influence their daily functioning, relationships with others, relationship with themselves and their feelings about the future.

“I think that everything else that came on board with what happened [death of mother] is like a big ball of craziness and I don't know if I am actually sane or not....I think it is all sort of pushed back and hopefully one day it doesn't just break out and send me nuts.” (Angela)

Participants whose mothers' died reported experiencing ongoing emotional and psychological distress. This related to not only missing her, and longing for their relationship, but also dealing with grief and the psychological aftermath of depression and anxiety. They had no hesitation in describing this as a traumatic experience.

“I think I have taken it really, really hard. I have a lot of problems with depression, and a lot of problems with relationships with people. I have a big fear of people leaving....sometimes I become resentful that mum died because I think I wouldn't have all these problems.” (Emily)

“Just feeling empty, empty at the fact that she wasn’t there anymore. It’s the emptiness of her not being there, of knowing that she’s not there and there’s nothing you can do about it.” (Angela)

What made this loss even harder for daughters to deal with was the unexpected reality of death in their lives. Since they were young, they had always thought their mothers would be around, and had never contemplated a world that didn’t include her.

“I was in denial....she’s your mother, you think she is always going to be there...”  
(Emily)

In an attempt to make meaning out of the intense emotions of loss and grief, it was important for participants to have keepsakes or recollections, thereby enabling them to feel they had a piece of their mother with them; thus reducing the fear that they were going to forget her. A photo, diary, piece of jewellery, scarf, or even just feeling like they could see their mother in themselves, and their siblings, became valuable reminders and were highly treasured. It was a way for the participants to hold on to the memories, and a physical presence of their mothers, and to incorporate her presence into their lives, despite her absence. Similarly, such mementos also provided a means for their children to learn about their grandmothers.

“Having pieces of mum’s jewellery is something that is really important to me, and something I can pass on to my children one day. I wear them on special occasions or during hard times, and I don’t feel so alone. It helps me to feel like she is still with me in some way.” (Rachel)

“I don’t do it so much now but I’ll go in and sit with the scarf and say ‘oh you know mum, blah, blah, blah’. You might feel like a bit of a dill sitting there (laugh) but you just do it. There’s a photo of mum in my dining room and I walked past it yesterday and I said ‘happy mother’s day mum’. You can’t just put her away and pretend that she wasn’t there. I think you need something

around to still feel close to her. I feel comfort in having little things of hers around.” (Linda)

Whilst physical similarities to their mothers could provide comfort and a sense of connection, it was for some also problematic. Physical similarities became a double edged sword as this sense of closeness could also equate to a sense of vulnerability.

“People often tell me how much I am like my mother, that physically and personality wise there is a strong similarity. I like that I am like her, I like to feel that connection, but it does increase the fear that I might share her fate.”

(Rachel)

Maternal death is permanent; it extends beyond the point of occurrence to influence past, present and future existence. Participants’ reflected on their past, which they felt strongly influenced their current lives and informed their perceptions, fears and choices for the future. Some participants reported realising that there would be endless future events and memories that their mother would never share. Christmas, birthdays and Mother’s Day, were viewed as regular celebrations that would now be a painful reminder of loss and longing. Other future events where they had always imagined their mothers’ presence included: milestone birthdays; graduations; the birth of grandchildren; engagements, weddings and even buying their first home. These life cycle events were now viewed with a mixture of excitement and sadness, of a life unable to be shared with their mother. On these days daughters would always feel a longing to have their mother with them; to share in her experiences, to hear her advice, to feel her arms around them.

“... my sister just got engaged and mum’s not going to be there for that and if one day I get engaged or one day I have kids...When I graduate she’ll never get to see that I’ve graduated. Things like that that you always wish that your mum was there for.” (Emily)



“My birthday you know, I know that it’s that one phone call that I don’t get anymore. Any special occasions are difficult times... You can have all your family there and you can have all your friends there but it’s not the same when all you want is your mum to see you.” (Linda)

They longed for the missed opportunity of getting to know their mothers beyond the parent/child relationship, as woman to woman. Many had lost their mothers when they were quite young, when they were still dependent on their mother as a carer and provider. They found themselves wondering what sort of relationship they would have had with their mothers as they matured, and what influence she would have had on their lives, and the women they were yet to become.

“I feel as though my mother died not knowing who I was. I was her daughter for thirty years until she died and I feel like I buried her with her not knowing who I was.” (Emily)

“I have always been a lot like my mother, and I like that. But I do wonder as I get older what our relationship would have been like, and how different my life might be if she was still alive.” (Rachel)

Some time had passed since the death of some of the participant’s mothers and they emphasised the fact that their mothers were still an important part of their lives, that she would never be forgotten. They reported that some days were more painful than others, but their mothers were always in their thoughts. It was also important for them to feel like they could move on with their lives, and attempt to reduce the negative impact of their mother’s death. At times they found this hard and expressed feeling guilty that they seemed to be forgetting their mother. Nonetheless it was important for participants to be able to reach a stage where they remembered their mothers with fondness and happiness instead of only reliving pain and tears.

“I think you get to a point where you do keep going, you get on with your life. I feel guilty sometimes because every now and then I pull myself back and go ‘oh, you’ve forgotten about her’, even though I haven’t I do feel guilty about that sometimes. But I have to be able to get on with my life and move forward and accept the fact that I can’t just call her.” (Emily)

The participants noted that whilst time does not heal all wounds, it could be just as dangerous to stay stuck in the pain of the past. They were trying to navigate themselves to a point of acceptance, and coping, within their new reality without their mothers.

The above findings demonstrate that both temporary and permanent loss of the mother daughter relationship has significant practical, emotional, social and identity implications for young women. Not only is the loss felt keenly at the time, and has developmental implications, this loss pervades lived experience across the years.

## **Discussion**

With growing incidence and prevalence of a cancer diagnosis, the empirical literature is predominantly focussed on the patient or survivor. There is a plethora of literature documenting the physical and psychosocial consequences of a cancer diagnosis (Buchmann, Conlee, Hunt, J., & White, 2013; Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Clough-Goor & Silliman, 2012; Glasser, Nielsen, Nielsen-Smith, & Gray, 2013; Howard-Anderson, Ganz, Bower, & Stanton, 2012; Mosher, Bakas, & Champion, 2013; Penedo et al., 2013; Rainville et al., 2012; Stanton, 2012; Treanor, Santin, Mills, & Donnelly, 2013) but the familial cancer experiences of daughters’ remains under-researched. As demonstrated in the introduction

section of this paper, relational distress could facilitate our understanding of familial cancer. Reconceptualising facets of relational distress to include developmental attachment, embodied and biographical identity, adds to the current body of knowledge. The findings clearly illustrate the applicability of these concepts, from the perspective of the daughters themselves. A further contribution is that a Heideggerian perspective illuminates the relationship between the existential crisis of cancer and relational distress. This complexity is discussed in detail below.

### **Relational distress**

Our findings indicated that all daughters experienced a lack of emotional support, comfort and security, as a result of their mothers' illness, which in turn created a sense of loss and grief, particularly for young children. This emotional and relational void created by mothers' absences was most keenly felt in the loss of day to day companionship. Paradoxically, mothers who usually provided the nurturing were also the source of the distress. There was variation in the length and degree of impact of the acute stage of the mother's cancer; but irrespective of this, daughters noted that they felt no relief from ongoing distress. They resoundingly believed that time did not heal all wounds and that cancer would be ever present in their lives.

For daughters who experienced maternal death, a two-fold sense of mourning, also documented in the literature (Cait, 2008; Oberhofer, 1990; Schultz, 2007), was common: mourning for the loss of their mother and mourning for missed opportunities and experiences (mourning for the might-have-beens). One way of ameliorating mourning was through access to keepsakes, as they allowed an emotional and physical connection to their mother to be maintained as a **continuing bond** (Cait, 2008; Neimeyer, Baldwin, & Gillies, 2006; Sussillo, 2005; **Walter, 1999**). Although the consequences of their mothers' death were ongoing, it was important for daughters to be able to construct a new reality where they could move past their acute pain (Bekteshi & Kayser, 2013; Maloney et al., 2012; Wenzel et al., 2012; Wiggs, 2011), their

challenge was to try and find new ways to be a daughter, and reconstruct their identity in her absence.

### **Developmental attachment**

The findings indicated that for all daughters being separated from their mothers temporarily through treatment, or permanently through death, created disconnection from the most important person in their lives; that is, they lost their secure base (Bowlby, 1969, 1988; Howe, 2011). Daughters gained insight into a world without their mothers; an unwanted physical and emotional possibility. Significantly, when considering daughters' recollections of their childhood, the concept of developmental attachment provides an insightful interpretation. As many families needed to relocate for treatment, physical proximity was often not able to be maintained. Even when the mother was physically present in the home, emotional proximity was compromised as a result of treatment side effects, fatigue, illness and, as also noted by Clemmens (2009) the mother's own anxiety and depression. Difficulties in maintaining proximity posed further threats to emotional security and normative family life. Despite these difficulties, many daughters adopted caring roles, relocated with their mothers for treatment and sacrificed school and social activities

### **Embodied identity**

To alleviate their grief, daughters in this study, and in other research (Cait, 2008; Meyerowitz, 2005; Neimeyer et al., 2006; Schultz, 2007; Sussillo, 2005) identified with physical characteristics shared with their mothers as a way of carrying part of her with them. Daughters took pride looking like their mothers and sharing physical characteristics such as hair and eye colour and body shape. But paradoxically, this inter-embodiment also caused distress as similarities also represent vulnerability to cancer. When daughters recounted their own sense of their breast development it was imbued with trepidation. When reporting on their present

perceptions of breast health, every lump or hormonal change was a possible threat. Thus, whilst breasts represent motherhood, femininity and sexuality, for daughters in this study they are also a threat to mortality. Some were considering prophylactic mastectomy.

Findings indicated that daughters observed their mothers' physical suffering throughout chemotherapy, surgery and treatment side effects. Memories of their mother were tainted by recalling her losing her hair, severe fatigue, nausea, vomiting, disfigurement and in some cases palliative care. All of these experiences, whether temporary or permanent, represent the physical deterioration of the body and the possibility of death. Through the eyes of the daughter, this is a threat to her own physical integrity.

Daughters perceived that the permanent loss of their mothers had consequences for their ability to understand or predict their experiences of menstruation, pregnancy, childbirth, menopause and ageing. The inter-embodiment is fractured through the mother's death, consequently, the witnessing and sharing of the gendered body perishes with the mother, thus the connection is severed.

### **Biographical identity**

As demonstrated throughout the discussion, a mother's illness, and in some cases death, strongly influenced daughters' lives. The daughters, whether they experienced temporary or permanent loss, shared common experiences of fear, uncertainty, anxiety and a disconnection from their once familiar world. Biographical identity is reshaped as daughters respond to their disrupted attachment.

To cope with this biographical fragmentation daughters are required to adopt a modified role within the home. Daughters' experience pressure and conflict between the expectation to remain in normative roles (such as school, sport and peer group interests), and wanting to be

with their mothers, even at times required to symbolically replace her, that is to fill the physical and emotional void within the family. This can either be positive in providing focus and structure, or negative in adding additional emotional and physical burden (Burles, 2006; Davey, Gulish, Askew, Godette, & Childs, 2005; Grabiak, Bender, & Puskar, 2007; Kim, Wellisch, & Spillers, 2008; Lenhardt & McCourt, 2000; Meyerowitz, 2005; Oktay, 2004, 2005; Pill & Zabin, 1997; Puterman & Cadell, 2008; Schultz, 2007).

With regard to biographical identity, Frank's narratives (1995) are instructive. Daughters who appear to be managing well and who are occupying the maternal role, can be viewed as on a heroic quest (Frank, 1995; Little et al., 2001; Miles Little, K Paul, C Jordens, & Emma-Jane Sayers, 2002; Miles Little & Emma-Jane Sayers, 2004). Part of this behaviour is adaptive to the disruption to attachment, yet it is also arguably an unfair pressure shouldered by children and young people. Additionally, the restitution narrative, which is a story of restoration to good health, and the triumph of treatment, is the most socially accepted and desired by daughters. Again is partly reactive to the disrupted attachment, and is an attempt by daughters to 'normalise' the relational distress. However, this restitution narrative acts to inhibit daughters' emotional expression of loss, grief and fear. By contrast, Frank's chaos narratives is in fact anti-narrative, with no sequential plot; it is hard to hear and hard to tell (Pascal, 2006). The findings point to ongoing emotional and psychological distress, including grief, anger, depression and anxiety. It is the chaos narrative which begs expression and has been largely overlooked in the existing literature.

The integration of these concepts are represented in figure 1.

Figure 1: Conceptualising relational distress

### **A Heideggerian post-script**

It is not within the scope of this article to provide a full Heideggerian analysis of maternal absence, as illustrated by these findings. What is possible is to consider key Heideggerian concepts as way of understanding the depth of daughters' lived experience of maternal absence, and also as a unifying conceptual framework for the current theories about relational distress, attachment disruptions and embodied and biographic identity.

From a Heideggerian perspective, daughters begin their cancer experience randomly "thrown" (Heidegger, 1962) into a pre-existing world of familial perceptions, genetic realities, and social constructions of cancer. For example, illness narratives (Frank, 1995; Mattingly, 1998) and gendered embodiment (Clemmens, 2009; Merleau-Ponty & Smith, 1962) precede daughters' personal lived experience, but nonetheless assist to shape perceptions. A mother's diagnosis of breast cancer serves to radically alter daughters' Being-in-the World (Heidegger, 1962), that is her existence in and engagement with the world around her. Being-in-the-World can be signified by relationships, embodiment and temporality (Boss, 2001; Merleau-Ponty & Smith, 1962; Munhall Jones, 1994), taken together these are indivisible lived experiences. Daughters' relational Being-in-the-World can be understood as fractured in the wake of a cancer diagnosis. Relational distress and, depending on the age of the daughter, developmental attachment issues, may arise. Embodiment, particularly the gendered and familial embodiment, becomes a source of angst (Heidegger, 1962). Witnessing their mothers' physical suffering, at the same time becoming aware of their own physical (and feminine) development, can heighten fears of cancer and death. As discussed earlier, biographical identity is also disrupted, with the familiar past receding and an unfamiliar future looming, understood as temporality (Heidegger, 1962). The present, in terms of average everyday experience (Heidegger, 1962), where much of this sorrow is realised, consists of altered social and family roles, maternal absence or loss, and the threat to family stability. Even when recalling the past and imagining their futures, from an

adult perspective, daughters are re-storying their lived experience. In Heideggerian terms, their *Dasein*, that is Being (existence) (Heidegger, 1962) is infused with ontological insecurity; how to make sense, and to continue to make sense, of this seemingly unending experience? The familiar and familial world is no longer, and becomes *unheimlich*, literally translated as unhomely, metaphorically appropriate to the daughters in this study, who have lost their familial secure base.

Being-with-Others is a core component of Being-in-the-World. People's lives consist of networks of interpersonal relationships and any experience of self and others occurs within this network. When trying to describe ourselves as human beings, we ultimately relate it, explicitly or implicitly, to our relationships with others in our world (Becker, 1992). There were many central relationships within the participant's lives, but none were as significant as the mother/daughter relationship.

A mother's Being-With is experienced not only in her presence in her daughter's life, but also in her absence. In remembering the deceased in mourning, those who are left behind are still present, in a mode of respectful solicitude (Heidegger, 1962). Those loved ones that leave through death are no longer present in the same reciprocal relationship, but can still have a presence in daughters' lives (Heidegger, 1962). That is to say that, for example, when a ring gets handed over through generations it does not simply change in location, or time. It is historicized through what has happened to it temporally; it becomes a way that the deceased still remain in the world with their loved ones (present and future) (Heidegger, 1962). These objects imbued their mother's spirit and provided comfort when they needed to feel her presence and maintained, albeit an altered, Being-With relationship.



Regardless of the length of time since maternal loss, the intensity of the experiences remained immediate. These memories were significant to daughters' current Being-in-the-World and pivotal to who they were and their future choices. Whether projecting back to what has been, contemplating the present or projecting towards the future, cancer and more specifically for some, the death of their mothers, forever reshaped daughters' existence.

From a Heideggerian perspective the findings in this article reinforce that the life world, is experienced in the context of Being-with-Others, and that our identity is formed within relationships (Heidegger, 1962). That is, we are social and contextual as human beings and our relationships are temporal; influencing past, present and future experiences (Heidegger, 1962). In Heideggerian parlance, we are, literally, beings in time (Heidegger, 1962), and this fits well with the notion of biographical identity. Conversely, within the familial cancer experience, the impact of Being-without is profoundly life altering, and shatters daughters' temporal continuity of self (Little et al., 2001; Miles Little et al., 2002; Miles Little & Emma-Jane Sayers, 2004). Again, this chimes well with biographical identity as an aspect of relational distress. Heideggerian phenomenology provides a new framework for understanding relational distress, framed within temporary or permanent loss of ones mother to familial breast cancer (see figure 2 below).

Figure 2: Heideggerian conceptualisation of familial cancer

## Conclusions

A mother's diagnosis of breast cancer can have significant implications for the family unit and in particular, the mother/daughter relationship. This research has demonstrated that daughters' experience significant psychosocial consequences as a result of their mother's diagnosis. Relational distress and the aspects of disrupted attachment, embodiment and biography provide a new way of understanding daughters' experiences of maternal absence due to breast cancer. This provides a sociological, rather than pathologising context, at the same time acknowledging distress (as a social construct); that is linking micro and macro experiences. The addition of a Heideggerian perspective adds a layer of existential meaning, highlighting the importance of being with and being without, and temporality. Taken together, relational distress and a Heideggerian perspective offer a nuanced analysis of this profound life experience, thus extending the normative psychological interpretation.

Additional research and resources are needed to further understand, and adequately respond to, the needs of daughters during their mother's diagnosis and treatment. Subsequently, a longitudinal study may provide further insight into the temporal impacts of maternal cancer. Likewise, similar studies exploring maternal cancer within different ethnicities, and from the perspective of sons, may aid in addressing the lack of knowledge in this area. Particular emphasis needs to be placed on addressing the long term and pervasive consequences for those whose mothers die as a result of their diagnosis.

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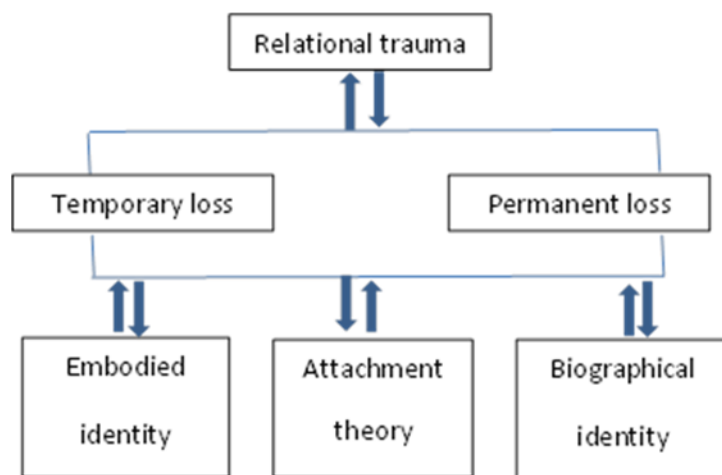
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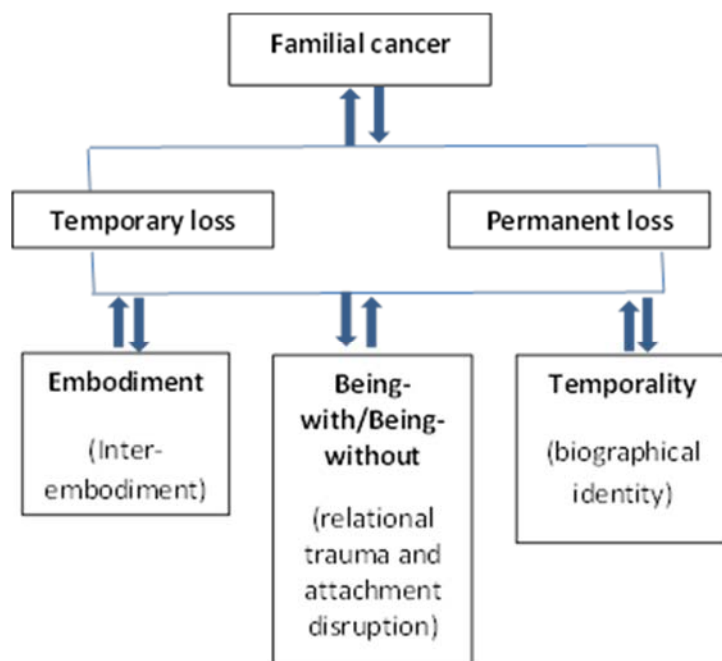


Pseudonym	Age	Number of family members diagnosed	Experienced maternal death	Years since familial diagnoses
Laura	33	>10	No	16
Sally	20	2	No	9
Natalie	34	2	Yes	15
Bethany	20	9	No	8
Melissa	30	4	No	15
Sophie	19	4	No	9
Jennifer	24	1	No	10
Claire	18	3	No	4
Kate	27	2	No	14
Kathryn	32	4	No	10
Donna	26	>3	No	8
Tammy	34	3	No	30
Megan	34	3	Yes	23
Linda	24	1	Yes	16
Angela	21	1	Yes	13
Rachel	24	3	Yes	10
Amy	25	7	Yes	12
Emily	34	1	Yes	10

**Table 1.** Participant Characteristics



**Figure 1.** Conceptualising Relational distress



**Figure 2.** Heideggerian conceptualisation of familial cancer